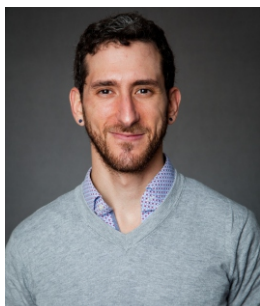


## Invited Article

### Ethical Living Donation Depends on Independent Advocacy

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Living organ donation is a unique area of medicine. It is one of the only clinical practices that will impose physical risks on a patient - the donor - without providing any potential medical benefits to this patient. Such a practice is justified by four facts: (1) The risks to the donor must be sufficiently low; (2) The likely benefits to the potential transplant recipient must be sufficiently high; (3) the donor must give full informed consent; and (4) the risk/benefit calculus for the potential donor must be expanded to include spiritual, emotional, and relational benefits and risks. The dire need for more transplantable organs, and the pressures on hospitals to obtain organs for transplant, mean

that no clinical team performing living donations should have sole responsibility for meeting these requirements. Living donors need and deserve independent living donor advocacy. This protects not just donors, but living donor programs, and the field of transplant medicine.

All patients deserve advocacy. But the people who usually serve as patient advocates for other medical concerns – loved ones and clinicians – sometimes have insurmountable conflicts of interest in the living organ donation context. The potential transplant recipient, or someone who cares about both the donor and the potential recipient, cannot be expected to objectively advocate for the donor's best interest. It would also be unreasonable to expect clinicians and clinical programs that have stakes in living donor transplant outcomes to objectively assess whether donation is in an individual's best interest. Doing so requires independence from both the recipient and from the hospital, such that one's allegiance is only to the donor.

To be effective, Independent Living Donor Advocates (ILDAs), cannot operate alone. While ILDAs must be knowledgeable about living donation and able to convey general statistics, the medical team understands the clinical risks specific to the donor and potential clinical benefits for the recipient. To meet the ethics requirements of ensuring an appropriate clinical risk/benefit profile, these must be conveyed to donors in ways they can understand, and the clinical team is best suited for this job. But for potential donors to provide informed consent - meaning they comprehend clinical risks in context of their own values and goals, including navigating feelings of duty to family while prioritizing their own interests - requires an ILDA who only cares about the donor.

Even members of the living donor team trained in psychology and social work cannot overcome assessment barriers built into hierarchical doctor-patient relationships. Some potential donors do not want to let clinicians down, or do not trust that what they tell the donor team will not somehow get back to the recipient. When the ILDA enters the evaluation and tells the patient, "I'm here to support you, to

help you think through what it means to donate, I only care about you, I don't work for these guys," the patient often opens up in ways they did not previously.

This allows the ILDA to ensure that the final ethics requirement of living donation is met – that the potential donor can weigh risks and benefits beyond the physical. Donors often experience extraordinary psychosocial benefits, knowing they helped save someone's life. Many societies, cultures, and religions see no morally greater act. When individuals find such meaning, it can enhance their own quality of life. But this benefit cannot be assumed. No matter how clinically safe, living donation involves invasive surgery with recovery time, which can mean changing or canceling significant life plans, losing income, complications for bodily identity, unreasonable expectations for relationships between donor and recipient post-donation, and feelings of failure or guilt if the transplant is not successful. No person should be expected to participate in living donation against their will, under undue influence, or without adequate information or capacity.

Parsing out the potential psychosocial, emotional, and relational implications of living donation is challenging. It is hard to find someone not employed by the transplant program with the requisite time and expertise. And most cases are not clear-cut examples of coercion, like donors being promised large sums of money or facing threats of physical force. Often, potential donors are conflicted, wanting their loved ones to survive and live better, but are simultaneously scared and feeling guilty about not wanting to reroute their lives. It is often unclear even to well-trained ILDAs how to strike the balance between enabling the patient's autonomy, while protecting the patient. But having an ILDA as a required part of the evaluation lends integrity and credibility to the process. The lives of potential donors are always as important as the lives of potential recipients. Giving potential donors someone "in their corner" can preserve trust in transplant, which ensures donors keep coming forward.

*About the author*

*Brendan Parent, JD is Principal Investigator on government and foundation grants studying ethics and regulation of transplant research. Parent serves as an independent living donor advocate, an advisory board member for the National Kidney Foundation, and a member of the national donation leadership council for The Alliance. He provides ethics consultation for transplant and medical research programs across the United States. Parent's current work also focuses on ethics challenges surrounding determination of death by neurologic criteria, research on the deceased, and big data and artificial intelligence in health research. He has published academic articles in peer reviewed journals spanning law, medicine, science, sports, and ethics, and his work has been featured in the Washington Post, The NY Times, Wired, Chicago Tribune, The Guardian, and on NPR. Previously, he was a legal fellow for the New York Task Force on Life and the Law, the first Rudin Post-Doc in the NYU Division of Medical Ethics, and received his JD from Georgetown University Law Center.*

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